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ORIGINAL ARTICLE

A survey of patient and caregiver experience with malignant pleural mesothelioma

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Abstract

Background Malignant pleural mesothelioma (MPM) is a rare cancer with poor prognosis. As there is little information on the lived experience of MPM, our aim was to document the experience of MPM patients and their caregivers.

Methods Surveys for MPM patients and caregivers were developed from previous interviews with patients, caregivers, and health professionals, about treatments and decision-making. Participants were recruited from two hospitals, government compensation body, and support groups.

Results Survey responses were received from 78 MPM patients and 106 caregivers from January to September 2014. Patients: 85% male, median age 69 years, median time since diagnosis 15 months. Caregivers: median age 68, 91% female, 90% spouse of MPM patient, 95% bereaved.

Most participants felt informed about treatment options but only 69% thought all treatment options were discussed. Chemotherapy was discussed most frequently (92–95%); ~80% had sufficient information for decision-making. Decision regarding chemotherapy was made by patient considering doctor's opinion (24%), doctor and patient equally (18%), and doctor (17%). Participants 'agreed'/'strongly agreed' that they made the right decision about chemotherapy (patients 81%, caregivers 60%), but 5% and 16%, respectively, regretted the decision.

Most participants received 'sufficient' support (71%). A quarter reported seeing cancer nurse specialists. Palliative care referral: 31% patients, 85% caregivers. Caregivers would have liked to talk to someone by themselves (41%), more time with doctors (30%), psychological support (29%), and clearer information (31%). Bereaved caregivers requested grief counselling (39%) and post-death consultation with specialists (23–25%).

Conclusions Satisfaction with treatment was high, but participants identified need for improved communication and quality information, discussion about all treatments, end-of-life assistance, and caregiver support after the patient's death.

Keywords Malignant pleural mesothelioma · Patient experience · Caregivers · Decision-making · Chemotherapy

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Introduction

Malignant pleural mesothelioma (MPM) is a rare cancer of the mesothelial lining of the lungs, related to asbestos exposure [1, 2]. It has a poor prognosis with median survival 9–13 months, and heavy symptom burden. Combination chemotherapy potentially improves survival, with a median survival benefit of 3 months [3–5], and improvement in quality of life [6, 7].

Information regarding the experience of people and families living with MPM is limited: particularly, peoples' perception of the impact of the disease and treatments received, how decisions are made regarding treatment, support received, and unmet needs. What is available is mainly restricted to the United Kingdom [8–10], with one case study series from rural

Victoria, Australia that interviewed two people with MPM and six family carers [11].

We previously conducted qualitative interviews to explore the perspective of MPM patients, caregivers, and health professionals who treat mesothelioma, about chemotherapy use for people with MPM, decision-making, health care systems, and treatments [12]. In the present study results from the qualitative study were used to develop surveys to quantitatively evaluate people affected by MPM (patients, caregivers, and health professionals) to investigate the diagnostic process, potential barriers and enablers to treatment, decision-making, informational needs, support required, and other issues associated with living with, and caring for people with, MPM. Here we report on the experience of people diagnosed with MPM and caregivers of MPM patients. Health professionals' views will be reported separately.

Methods

Development of survey

Survey item generation was based on results from qualitative interviews with MPM patients, caregivers, and health professionals who treat MPM [12]. Themes identified from the interviews were used to develop surveys for the following populations: (1) people diagnosed with MPM, (2) caregivers of individuals diagnosed with MPM, (3) doctors, and (4) specialist nurses caring for people with MPM. Survey questions were reviewed by: six consumers affiliated with the Asbestos Diseases Research Institute (ADRI) or Asbestos Diseases Foundation of Australia (ADFA), six specialist doctors and nurses involved in MPM treatment, staff from ADRI, MPM researchers from Southern Cross University, and a lawyer experienced in representing clients with MPM. Reviewers were asked to comment regarding the clarity and face validity of questions, any additional issues for inclusion, and respondent burden. The final survey consisted of 62 items, including free text for comments about anything respondents felt was not included (Appendix 1).

Involvement in decision-making

A modified version of the Degner scale assessed involvement in treatment decision-making [13]. The five-item Decision Regret Scale assessed decision regret; this has been widely used, and demonstrates good internal consistency [14]. A score of 1–24 is regarded as mild regret, and 25–100 is considered moderate to severe regret [15].

Data collection

Surveys were designed to be completed anonymously online or on paper, depending on respondent's preference. The electronic forms, developed using the REDCap data capture platform [16], generated a hyperlink e-mailed to potential participants. Paper questionnaires were mailed with a reply-paid envelope. The study was approved by the Concord Repatriation General Hospital Health Research Ethics Committee (HREC/12/CRGH/122), with return of the survey implying informed consent.

Participants

Participants were recruited using several strategies, including mail-out of an invitation letter and the survey from icare Dust Diseases Care [17] to all registered MPM patients as at January 2014. icare is a New South Wales (NSW) government body providing financial compensation and care to people diagnosed with MPM due to occupational exposure. It is estimated that 70% of NSW MPM patients are registered with icare [17]. An invitation letter and survey was sent by icare to caregivers who had participated in our previous icare project [18]. Patients diagnosed with MPM were recruited from two Sydney teaching hospitals (Concord and Royal Prince Alfred Hospitals) via a study flyer. Patients and caregivers were recruited from advertisements placed in newsletters and on websites of mesothelioma support groups throughout Australia (see Acknowledgements) and the ADRI. The study flyer was provided to prospective participants by two law firms specialising in MPM compensation.

Place of residence was determined from post code, with location type (metropolitan, regional, remote) categorised according to the Accessibility and Remoteness Index of Australia (ARIA) [19].

Data analyses

Descriptive statistics were generated using Excel 2013. A *t* test was used to determine differences between patients and caregivers for the Decision Regret Scale using SPSS Statistics version 24. The sample size was one of convenience and feasibility due to the rarity of MPM.

Results

Surveys were collected between January and September 2014, with 184 received: 78 from people diagnosed with MPM and 106 from caregivers. The response rate was not able to be accurately determined due to the various recruitment methods used and anonymity of respondents, but using the icare mail-

out details patient response was estimated to be 61/148 (41%) and caregivers 56/124 (45%).

The patient group ($N = 78$) was predominantly male (85%) with a median age of 69 years (range 44–92). Median time since diagnosis was 15 months, with some long-term survivors (range 1–82 months). Caregivers ($N = 106$) were slightly younger, were female (91%), and 95 (90%) cared for a spouse/partner with MPM. Almost all caregivers (95%) were bereaved, with median time since diagnosis of the individual they cared for 72 months (Table 1).

Leading to diagnosis, participants (patients and caregivers) reported MPM patients first seeing their general practitioner (GP) or a specialist about the following symptoms: shortness of breath 102/184 (55%), cough 64 (35%), pain 65 (35%), persistent cold/flu symptoms 27 (15%), weight loss 24 (13%), and fever/sweats/chills 17 (9%), with 6 (3%) stating that the disease was detected during routine screening for asbestos exposure and 17 (9%) discovered incidentally, usually during imaging for another reason. Most patients reported a time frame of 0–4 weeks from first noticing symptoms until seeing a doctor (52/, 67%), and for time from first doctor's appointment until diagnosis (46, 59%) (Table 2).

Most patients (72/78, 92%) reported imaging pre-diagnosis, with respiratory physicians and surgeons most involved in diagnosis (52, 67% and 48, 62%, respectively) and informing patients of their diagnosis (27, 35% and 37, 47%). Caregivers reported similar results. In total, 32 (41%) patients perceived a delay in their diagnosis, with the main reason being health professionals unable to make a definitive diagnosis (12, 15%). Most participants knew very little about MPM prior to diagnosis, with only 23% of patients and 14% of caregivers knowing more than 'a bit'.

Information seeking

After diagnosis 66/78 (85%) patients and 91/106 (86%) caregivers reported seeking information about MPM, most commonly from online sources (52 (79%) patients, 66 (73%) caregivers). Of patients seeking information online, 19/52 (36%) rated it as 'often' or 'almost always' helpful. Thirty-two (62%) patients and 40 (61%) caregivers reported that online information was 'overwhelming' or 'somewhat overwhelming'. Patients most commonly discussed information with their treating specialist(s) (44/66, 67%) or family members/friends (43, 65%). Overall, 27 (35%) patients would have liked more information on what to expect with their disease, and 61 (58%) caregivers about what to expect in caring for someone with MPM (Table 2).

Treatment for MPM

Almost all participants (99%) reported discussing treatment options with a health professional. Options most frequently

Table 1 Participant demographic information

	MPM patients ($N = 78$)	Caregivers ($N = 106$)
Age at time of survey (years)		
Median (range)	69 (44–92)	68 (34–87)
Missing	1	2
Gender		
Male	66 (85%)	8 (8%)
Female	12 (15%)	96 (91%)
Missing	0 (0%)	2 (2%)
Education level completed		
Year 10 or less	35 (45%)	60 (57%)
Year 12	3 (4%)	7 (7%)
TAFE/vocational or trade certificate	26 (33%)	12 (11%)
Tertiary/undergraduate	13 (17%)	18 (17%)
Post-graduate qualification	1 (1%)	8 (8%)
Missing	0 (0%)	1 (1%)
Time since diagnosis (months)		
Median(range)	15.0 (1.0–82.0)	72.0 (8.0–218.0)
Missing	7	15
Work status	At diagnosis	At survey
Paid work	30 (38%)	11 (10%)
Retired	41 (53%)	67 (63%)
Home duties	1 (1%)	11 (10%)
Full-time carer duties	0 (0%)	2 (2%)
Unemployed	4 (5%)	2 (2%)
Other	2 (3%)	11 (10%)
Missing	0 (0%)	2 (2%)
Health status of person care(d) for	N/A	
Well, not on treatment		1 (1%)
On treatment		3 (3%)
On treatment break		1 (1%)
Deceased		101 (95%)
State of residence		
New South Wales	60 (77%)	69 (65%)
Queensland	9 (12%)	21 (20%)
Victoria	1 (1%)	4 (4%)
South Australia	2 (3%)	3 (3%)
Western Australia	1 (1%)	1 (1%)
Northern Territory	1 (1%)	0 (0%)
Unknown	4 (5%)	8 (8%)
Residential location type		
Metropolitan	67%	58%
Regional	27%	32%
Remote	1%	1%
Unknown	5%	8%
Self-reported ECOG performance status[a]		
Patient status at time of survey		N/A
0	7 (9%)	
1	40 (51%)	
2	21 (27%)	
3	8 (10%)	
4	2 (3%)	
Asbestos exposure of respondent		
Yes	74 (95%)	60 (57%)
No	0 (0%)	34 (32%)
I do not know	4 (5%)	10 (9%)
Missing	0 (0%)	2 (2%)
If yes, nature of exposure		N/A
Occupational	69 (93%)	
Home renovations as an adult	12 (16%)	
Childhood exposure	3 (4%)	
Other	1 (1%)	

MPM malignant pleural mesothelioma, N/A not applicable

[a] ECOG (European Cooperative Oncology Group) Performance Status: 0 = fully active, able to carry on all pre-disease performance without restriction; 1 = restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g. light housework, office work; 2 = ambulatory and capable of all self-care but unable to carry out any work activities, up and about more than 50% of waking hours; 3 = capable of only limited self-care, confined to bed or chair more than 50% of waking hours; 4 = completely disabled, cannot carry on any self-care, totally confined to bed or chair

Table 2 Mesothelioma diagnosis and information seeking

	MPM patients ($N = 78$)	As reported by caregiver ($N = 106$)
Procedures leading to diagnosis		
Imaging	72 (92%)	96 (91%)
CXR	62 (79%)	84 (79%)
CT scan	59 (76%)	66 (62%)
PET scan	12 (15%)	23 (22%)
Unsure	1 (1%)	9 (8%)
Biopsy		
By radiologist or respiratory physician	28 (36%)	42 (40%)
By surgeon	44 (56%)	58 (55%)
HCPs involved in diagnosis[a]		
Medical oncologist	23 (29%)	34 (32%)
Respiratory physician	52 (67%)	74 (70%)
Surgeon	48 (62%)	64 (60%)
General practitioner	34 (44%)	58 (55%)
Cancer nurse specialist	2 (3%)	11 (10%)
General nursing staff	6 (8%)	10 (9%)
Other	4 (5%)	5 (5%)
Time from first symptoms until saw doctor		
0–4 weeks	52 (67%)	58 (55%)
5–7 weeks	6 (8%)	16 (15%)
2–3 months	9 (12%)	8 (8%)
4–6 months	4 (5%)	5 (5%)
> 6 months	4 (5%)	9 (8%)
Do not know	N/A	5 (5%)
Missing	3 (4%)	5 (5%)
Time from seeing doctor until got MPM diagnosis		
0–4 weeks	46 (59%)	42 (40%)
5–7 weeks	10 (13%)	21 (20%)
2–3 months	6 (8%)	10 (9%)
4–6 months	4 (5%)	13 (12%)
> 6 months	11 (14%)	15 (14%)
Do not know	N/A	3 (3%)
Missing	1 (1%)	2 (2%)
Informed of diagnosis by[a]		
Medical oncologist	13 (17%)	18 (17%)
Respiratory physician	27 (35%)	38 (36%)
Surgeon	37 (47%)	47 (44%)
General practitioner	14 (18%)	13 (12%)
Cancer nurse specialist	1 (1%)	0 (0%)
Other	0 (0%)	2 (2%)
Do not know	N/A	3 (3%)
If MPM diagnosis took a long time, why?		
Not applicable	46 (59%)	46 (43%)
Complications—chest infection	2 (3%)	5 (5%)
Difficulty seeing specialist	0 (0%)	8 (8%)
Delay for scan	0 (0%)	3 (3%)
Need for multiple biopsies	3 (4%)	7 (7%)
HCP could not make definitive diagnosis	12 (15%)	30 (28%)
Initially wrong diagnosis made	7 (9%)	17 (16%)
Did not follow up with HCP	2 (3%)	2 (2%)
HCP did not pursue diagnosis	3 (4%)	9 (8%)
Other	9 (12%)	20 (19%)
Main HCP looking after the patient[b]		
Medical oncologist	59 (76%)	53 (50%)
Palliative care physician	7 (9%)	23 (22%)
Radiation oncologist	2 (3%)	7 (7%)
Respiratory physician	12 (15%)	21 (20%)
Surgeon	7 (9%)	10 (9%)
GP	15 (19%)	30 (28%)
Cancer nurse specialist	6 (8%)	10 (9%)
No one	1 (1%)	1 (1%)
I do not know	N/A	1 (1%)
Other	1 (1%)	4 (4%)
Did you know about mesothelioma before diagnosis?		
I had never heard of it	15 (19%)	30 (28%)
I had heard of it but knew nothing or not much about it	29 (37%)	38 (36%)
Knew a bit about it	16 (21%)	23 (22%)
Knew a reasonable amount	14 (18%)	11 (10%)
Knew a lot about it	4 (5%)	4 (4%)
Did you look for information after MPM diagnosis		
Yes	66 (85%)	91 (86%)
No	12 (15%)	13 (12%)
Do not remember	0 (0%)	2 (2%)
If yes, where did you look?	N = 66	$N = 91$
Online	52 (79%)	66 (73%)
Spoke with medical professionals other than those involved in diagnosis	29 (44%)	37 (41%)
Spoke with other people with mesothelioma	13 (20%)	9 (10%)
Mesothelioma support organisation	16 (24%)	26 (29%)
Workplace safety officer/counsellor	1 (2%)	N/A
Union representative	2 (3%)	N/A
Friends or personal contacts	N/A	17 (19%)
Other	13 (20%)	13 (14%)
If you looked online	$N = 46$	$N = 61$
(a) Was the information helpful?		
Hardly ever	2 (4%)	7 (11%)
Occasionally	5 (11%)	6 (10%)
Sometimes	20 (43%)	17 (28%)
Often	11 (24%)	11 (18%)
Almost always	8 (17%)	20 (33%)

Table 2 (continued)

	MPM patients (*N* = 78)	As reported by caregiver (*N* = 106)
(b) What is your opinion about the information you found online?[a]	*N* = 52	N = 66
Was of good quality	15 (29%)	20 (30%)
Helped me understand MPM better	40 (77%)	48 (73%)
Helped me understand treatment options	22 (42%)	29 (44%)
Helped me understand my treatment(s)	13 (25%)	N/A
Helped me make decisions about treatment	11 (21%)	N/A
Was confusing	10 (19%)	11 (17%)
Some was inaccurate	4 (8%)	4 (6%)
Was upsetting	15 (29%)	28 (42%)
Was poor quality	2 (4%)	5 (8%)
Who did you discuss the information with?[a]	*N* = 66	N = 91
Cancer nurse specialist or general nursing staff	18 (27%)	19 (21%)
My GP	30 (45%)	50 (55%)
My treating medical specialist(s)	44 (67%)	62 (68%)
Another medical specialist(s)	7 (11%)	11 (12%)
Family members/friends	43 (65%)	45 (49%)
Workmates/colleagues	7 (11%)	N/A
Other people diagnosed with mesothelioma	8 (12%)	7 (8%)
Support organisations	5 (8%)	22 (24%)
Government body or department (e.g. icare, ComCare)	10 (15%)	21 (23%)
No one	2 (3%)	7 (8%)
Other	3 (5%)	10 (11%)

MPM malignant pleural mesothelioma, HCP health care professionals, CXR chest X-ray, PET scan positron emission tomography scan, CT scan computed tomography scan

[a] Respondents could choose more than one response so sum of percentages is greater than 100%

[b] Participants were asked to nominate the main health professional looking after their MPM or the person they cared for, but some nominated two or more so sum of percentages may be greater than 100%

discussed with patients and caregivers, respectively, were chemotherapy (95%, 92%), pleurodesis (78%, 77%), radiation therapy (68%, 65%), and radical surgery (55%, 52%). Of the 74 patients who discussed chemotherapy as an option, 77% reported receiving it (Table 3). Most respondents felt reasonably well informed about treatment options; 69% believed that all treatment options were presented. Main sources of treatment information were specialist 84%, written information 54%, cancer nurse specialist 37%, GP 34%, and nurse-led education session 30%.

In total, 19 (24%) patients reported declining at least one treatment option offered. Overall, 8 (10%) participated in a clinical trial. Of the 57 patients who received chemotherapy, 15 (26%) reported it was 'better than expected', and 17 (30%) 'as expected'. Within a month of starting chemotherapy, 13 (22%) reported feeling better and 17 (29%) 'the same'. Caregivers reported similar results for the person they care(d) for.

Overall, 42/184 (23%) participants reported using complementary therapies. In most instances 36/42 (86%) the treating specialist was reportedly aware of their use of complementary therapies.

Involvement of health professionals

Overall, patient and caregiver satisfaction with health professionals was high, with the majority reporting being 'very satisfied' with communication with their health professional(s) (Fig. 1). At the time of the survey, the majority of patients reported a medical oncologist as the main health professional looking after them (76%). When they had questions or things changed, the medical oncologist (30/78, 38%) or GP (12, 15%) was their first contact. GP involvement in their care was reported by patients to be 'managing their care' 8 (10%), 'a significant amount' 20 (26%), a 'reasonable amount' 24 (31%), 'very little' 18 (23%), and 'not at all' 7 (9%). Patient and caregiver perceptions of health professionals' communication about their care was that they talked to each other 'frequently' 63/184 (34%), 'almost always' 28 (15%), 'sometimes' 38 (21%), 'occasionally' 21 (11%), and 'hardly ever' 25 (14%).

Less than one third of patients reported being referred to palliative care. Of these 4 (17%) had been referred but chose not to see them yet. Caregivers reported that 90 (85%) of the people they care(d) for had been referred to palliative care.

Decision-making about treatment

When asked to think back to discussions about treatment options offered, 51 (65%) patients reported that their preference was to have chemotherapy, 13 (17%) not to have chemotherapy, and 9 (12%) were unsure. In making the decision whether or not to have chemotherapy, approximately 80% felt that they had sufficient information, and were clear about which choice to make. Further information regarding level of knowledge or support for the decision made is outlined in Fig. 2.

Patients and caregivers believed the decision whether or not to have chemotherapy was made by the patient but strongly considering the doctor's opinion (44/184, 24%), doctor and patient shared the decision (34, 18%), and doctor made the decision (31, 17%), whilst 7/78 (9%) patients stated that they had not yet had to make a decision. Overall, 33 (42%) patients reported their family had 'a lot' or 'moderate' influence in their decision regarding chemotherapy. Most caregivers were 'strongly' or 'moderately involved' in the decision-making process (88/106, 83%) and believed that they and the person they care(d) for were in 'complete agreement' about their

Table 3 Treatment options discussed, level of information received, and whether or not proceeded to treatment in those where it was discussed according to patients and caregivers of patients

Treatment options	Total discussed, *N* (%)	Outcome of treatments discussed				How informed were you/they?				
		Had/having treatment, *N* (%)	Treatment not needed yet, *N* (%)	Treatment unsuitable, *N* (%)	Chose not to have treatment, *N* (%)	Fully, *N* (%)	Reasonably, *N* (%)	Partly, *N* (%)	Poorly/uninformed, *N* (%)	Cannot recall, *N* (%)
Chemotherapy										
MPM patient	74/78 (95%)	57/74 (77%)	6/74 (8%)	2/74 (3%)	6/74 (8%)	48/74 (65%)	19/74 (26%)	5/74 (7%)	1/74 (1%)	0 (0%)
Caregiver	97/106 (92%)	70/97 (72%)	1/97 (1%)	12/97 (12%)	9/97 (9%)	54/97 (56%)	29/97 (30%)	6/97 (6%)	5/97 (5%)	1/97 (1%)
Pleurodesis										
MPM patient	61/78 (78%)	55/61 (90%)	1/61 (2%)	0 (0%)	1/61 (2%)	43/61 (70%)	11/61 (18%)	1/61 (2%)	3/61 (5%)	1/61 (2%)
Caregiver	82/106 (77%)	60/82 (73%)	0 (0%)	4/82 (5%)	0 (0%)	44/82 (54%)	22/82 (27%)	6/82 (7%)	4/82 (5%)	4/82 (5%)
Radiotherapy										
MPM patient	53/78 (68%)	29/53 (55%)	8/53 (15%)	3/53 (6%)	4/53 (8%)	35/53 (66%)	11/53 (21%)	2/53 (4%)	3/53 (6%)	1/53 (2%)
Caregiver	69/106 (65%)	41/69 (59%)	2/69 (3%)	10/69 (14%)	3/69 (4%)	35/69 (51%)	19/69 (28%)	4/69 (6%)	4/69 (6%)	1/69 (1%)
Radical surgery										
MPM patient	43/78 (55%)	16/43 (37%)	2/43 (5%)	10/43 (23%)	9/43 (21%)	28/43 (65%)	13/43 (30%)	1/43 (2%)	1/43 (2%)	0 (0%)
Caregiver	55/106 (52%)	13/55 (24%)	1/55 (2%)	19/55 (35%)	5/55 (19%)	28/55 (57%)	8/55 (15%)	4/55 (7%)	5/55 (9%)	3/55 (5%)
Other										
MPM patient	10/78 (13%)	5/10 (50%)	0 (0%)	0 (0%)	1/10 (10%)	4/10 (40%)	2/10 (20%)	0 (0%)	0 (0%)	0 (0%)
Caregiver	34/106 (32%)	5/34 (15%)	0 (0%)	2/34 (6%)	1/34 (3%)	7/34 (21%)	5/34 (15%)	2/34 (6%)	3/34 (9%)	5/34 (15%)

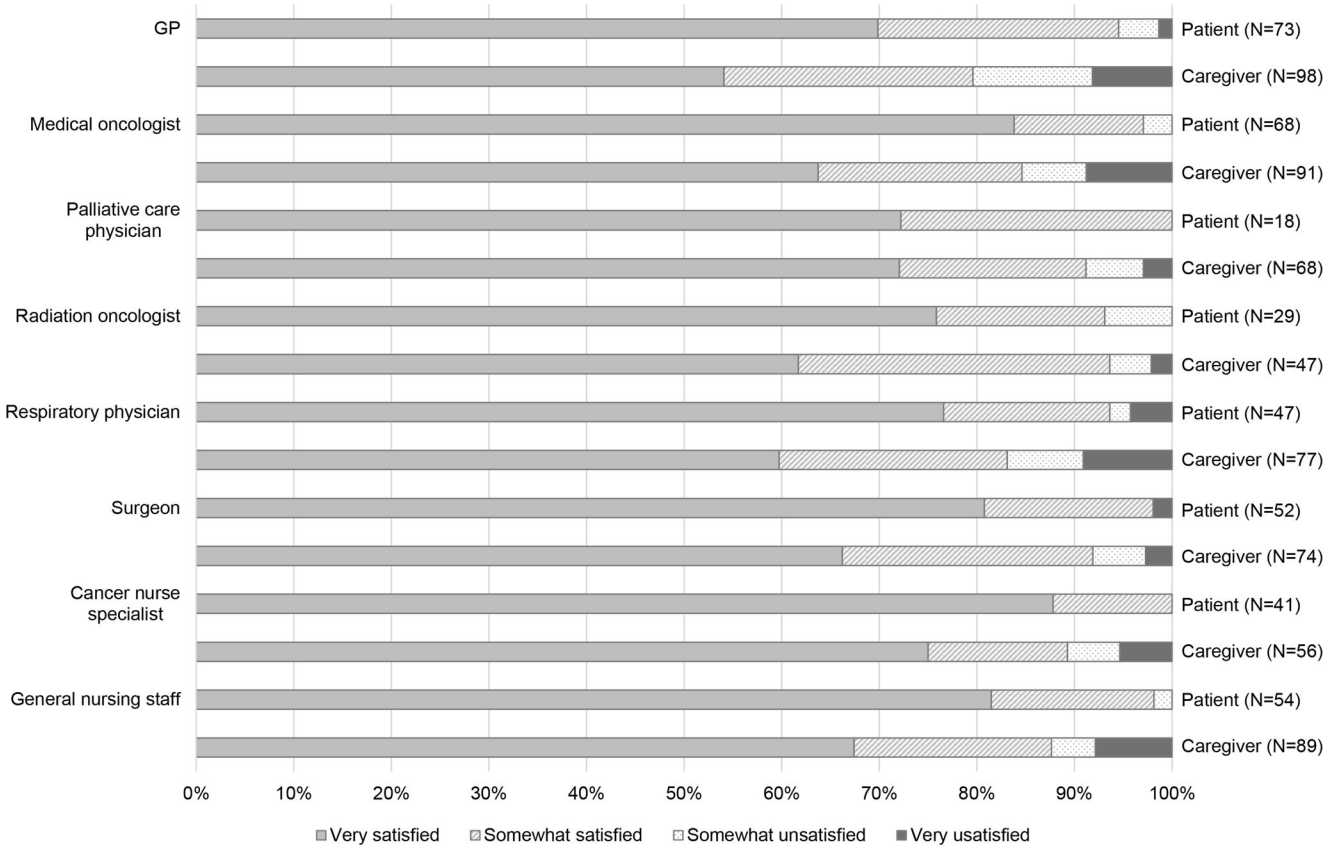

Fig. 1 Health care professionals seen and patients' and caregivers' level of satisfaction about communication with this clinician

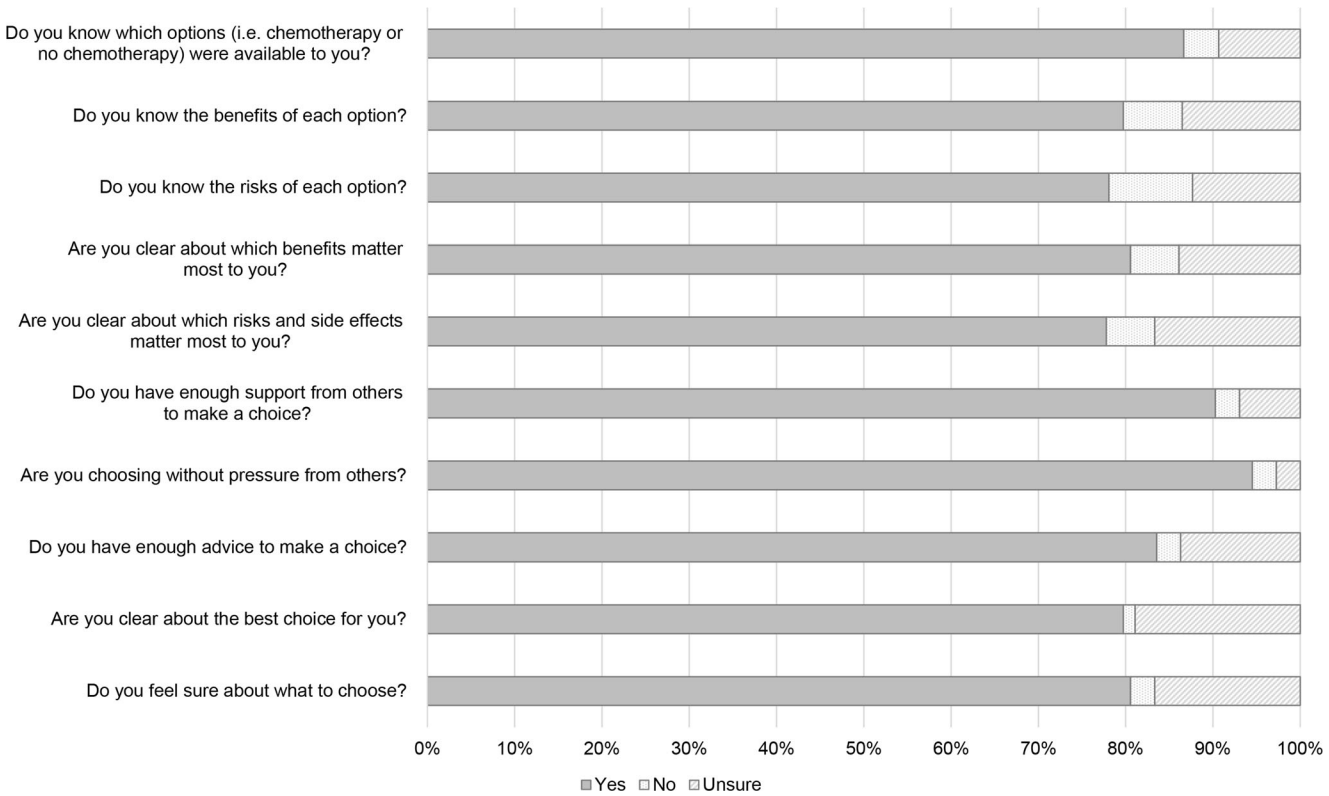

Fig. 2 Options considered by patients in decision-making regarding chemotherapy for malignant pleural mesothelioma ($n = 72–75$)

Table 4 Sources of support for people with mesothelioma and caregivers

Question	MPM patients ($N = 78$)	Caregivers ($N = 106$)
Main sources of support[a]		
Family /friends	73 (94%)	85 (80%)
GP	54 (69%)	53 (50%)
Cancer nurse specialist	21 (27%)	27 (25%)
General nursing staff	13 (17%)	21 (20%)
Medical specialist(s)	49 (63%)	30 (28%)
Palliative care	11 (14%)	56 (53%)
Mesothelioma support group	17 (22%)	25 (24%)
Lung cancer support group	0 (0%)	2 (2%)
Cancer helpline	0 (0%)	5 (5%)
I do not have any support	0 (0%)	2 (2%)
Other	2 (3%)	13 (12%)
What could help that you do not /did not have access to?[a]		
Support groups	4 (5%)	20 (19%)
Access to a cancer nurse specialist	4 (5%)	19 (18%)
More time with doctors to discuss matters	6 (8%)	32 (30%)
Counselling or psychological support	3 (4%)	31 (29%)
Clearer information on mesothelioma	5 (6%)	33 (31%)
Palliative care support	0 (0%)	14 (13%)
Practical support (e.g. social worker, physiotherapy)	3 (4%)	19 (18%)
Respite or time out from being a carer	N/A	21 (20%)
Someone to talk to by myself	N/A	43 (41%)
Other	11 (14%)	18 (17%)
Did you attend any support groups?		
Yes	23 (29%)	32 (30%)
No	53 (68%)	74 (70%)
Unsure	1 (1%)	0 (0%)
Missing	1 (1%)	0 (0%)
Reasons for not attending support groups?[a]	$N = 53$	$N = 74$
Do not like the idea	9 (17%)	5 (7%)
Not aware of existence	10 (19%)	26 (35%)
I do not need or want to attend	16 (30%)	15 (20%)
None in my area	8 (15%)	14 (19%)
Trouble getting there	2 (4%)	13 (18%)
Worried to see other MPM people who are sicker	11 (21%)	7 (9%)
Other	12 (23%)	19 (26%)
Practical supports received by patient?[a]		
None	8 (10%)	10 (9%)
Support not needed	10 (13%)	8 (8%)
Home help (e.g. lawn mowing, housework)	42 (54%)	38 (36%)
Home modifications	6 (8%)	21 (20%)
Home nursing	8 (10%)	40 (38%)
Home oxygen	8 (10%)	58 (55%)
Cancer nurse specialist	7 (9%)	16 (15%)
Exercise therapy	6 (8%)	3 (3%)
Physical therapy (e.g. massage)	2 (3%)	8 (8%)
Physiotherapy	8 (10%)	3 (3%)
Dietician	9 (12%)	12 (11%)
Medical equipment	5 (6%)	35 (33%)
Medication	14 (18%)	59 (56%)
Psychological support	3 (4%)	9 (8%)
Transport to medical appointments	6 (8%)	11 (10%)
Other	12 (15%)	31 (29%)
No support was available at time I was a carer	N/A	7 (7%)
Bereaved carers only: which would have been helpful following the death of person you cared for?[a]	N/A	$N = 101$
Post-death consultation with medical specialist		25 (25%)
Post-death consultation with palliative care specialist		23 (23%)
Post-death consultation with oncology psychologist		17 (17%)
Post-death consultation with cancer nurse specialist		12 (12%)
Grief counselling		39 (39%)
Phone call(s) from health care professional		21 (21%)
Phone call from community or support organisation		21 (21%)
Attending support group		13 (13%)
Other		29 (29%)

[a] Results may exceed 100% as participants could select more than one option

chemotherapy decision (79, 75%). Overall, 5 (6%) patients and 12 (11%) caregivers reported speaking to other patient(s) about chemotherapy before making a decision, and 13/184 (7%) participants stated that they would have liked to but did not have the opportunity. Of those who did speak to other people with MPM, 12/17 (71%) found it helpful.

Patients and caregivers were asked if they had regrets about whether or not to have chemotherapy. Patients reported (63, 81%) that they 'agreed' or 'strongly agreed' they made the right decision and only 4 (5%) regretted it. Most caregivers (64, 60%) agreed or strongly agreed they made the right decision, but 17 (16%) regretted the choice made. Overall, 55 (71%) patients and 52 (49%) caregivers agreed or strongly agreed they would make the same choice again, whilst 5 (6%) patients and 27 (25%) caregivers agreed or strongly agreed the choice did a lot of harm. Most patients (55, 71%) felt that 'the decision was a wise one', whilst for caregivers this was 45 (42%). Full data for the Decision Regret Scale was available for 57 patients and 59 caregivers. Regret was higher in the caregivers, with a mean score of 35.2 (SD 28; range 0–

95) compared to 19.9 (SD 19.9; range 0–70) in patients (p = 0.001).

Support for people with MPM and/or caregivers

The majority of MPM patients and caregivers reported receiving 'sufficient' support (131/184, 71%). Main supports for patients were family/friends (73/78, 94%), GP (54, 69%), and medical specialist (49, 63%); whilst for caregivers it was family/friends (85/106, 80%), palliative care (56, 53%), and GP (53, 50%) (Table 4). A quarter of patients and caregivers reported access to cancer nurse specialists but the specialty of these nurses was unclear. Practical supports received by patients are listed in Table 4. Caregivers reported higher rates of requiring home nursing, home oxygen, medical equipment, and medication than patients. Support groups were attended by 30% of patients and caregivers: 23 (42%) attended support groups specifically for people affected by MPM. Caregivers would have liked the opportunity to talk to someone by themselves (41%), more time with doctors (30%), access to psychological support (29%), and clearer information about MPM (31%).

Bereaved caregivers believed following the death of the person they cared for, they would have benefited from grief counselling (39/101, 39%) and a post-death consultation with a medical (25, 25%) or palliative care specialist (23, 23%).

Compensation

Almost all patients sought compensation for their MPM: 76/78 (97%) patients and 101/106 (65%) caregiver respondents. Of those that sought compensation most applied to a government compensation scheme either directly (119/177, 67%) or through a solicitor (21, 12%), and/or made a civil claim for damages (106, 60%). Patients generally learned that compensation may be an option from a doctor (109/177, 62%). Main reasons for applying for compensation were to 'leave their family financially secure' (118/177, 67%), for 'justice' (105, 59%), and 'needed money to help with treatment costs' (53, 30%). Of those applying for compensation, 171/177 (97%) participants reported being successful, and 6 (3%) had claims pending. In response to whether it was worth making a claim, 120/177 (68%) believed it was, 37 (21%) thought it was but the claim process could be improved, 7 (4%) that the compensation was not worth it, and 3 (2%) that the distress of going through the compensation process was not worth it.

Discussion

Our survey of caregivers and people diagnosed with MPM highlighted many issues common across groups. Time to accessing care after symptoms and diagnosis was generally achieved within 2 months of noticing symptoms, but half our patients perceived a delay in their diagnosis, and sometimes a delay of many months. Most participants knew little about MPM prior to diagnosis, and actively sought out information about MPM and treatment options, but the quality of the information was very variable. Almost two thirds rated the information accessed as overwhelming.

Prior to making treatment decisions, only two thirds of participants reported being reasonably well informed about options. The treatment option most frequently discussed with a health professional was chemotherapy (92–95%), with 77% of those it was discussed with going on to receive chemotherapy, and 8% choosing not to. This is higher than the chemotherapy utilisation rate determined in our earlier study, where according to evidence-based guidelines 65% of MPM patients had an indication for chemotherapy [20] but we estimated only 54% received it [18], possibly reflecting selection bias of this study population.

Whilst most patients and caregivers believed they made the right decision regarding chemotherapy, almost a quarter regretted their decision and thought their choice had caused harm. This regret was higher in caregivers, where the mean score was in the moderate-severe range, compared to mild regret for patients. The wording of the question did not specify whether participants thought chemotherapy or lack of chemotherapy had caused harm, but almost all participants who regretted the decision had received, or the person they cared for had received, chemotherapy, so it is likely the former. Patient and caregiver decisional regret has been investigated in non-thoracic oncology settings, where adverse physical health outcomes and greater anxiety were risk factors for decision regret [21]. A study assessing decisional regret in people with lung cancer undergoing chemotherapy reported that only 7% of patients had decision regret [22]. Our results suggest a different experience in the MPM population but may be skewed by caregiver perceptions. Decision regret may be influenced by stage of disease, and as most caregivers were bereaved, their perspective is likely to have been impacted by this, particularly if it was a difficult death.

Half the participants reported that they had discussed the option of 'radical surgery', and approximately a quarter of these stated they had received it. This highlights a probable lack of understanding about what radical surgery is, although a definition had been provided as meaning an extrapleural pneumonectomy at the start of the survey. Our results, including participants' free text comments regarding wanting more information about all treatment options, emphasise the importance of health care professionals discussing with patients and families what surgical cytoreduction is, and why it is not suitable for most patients, to avoid confusion or misplaced concerns this option was not fully explored, or would have been possible if the diagnosis had been made earlier.

Satisfaction with overall care provided by health professionals was high, but caregivers tended to be less satisfied than patients. This may be because patients were earlier in their journey, some were long-term survivors, and most still had reasonable performance status, whereas almost all caregivers were viewing the experience through the lens of bereavement. This could also explain differences in referral rates to palliative care between the two groups, with only 31% of patients having seen a palliative care physician, but 85% of caregivers reporting palliative care involvement. However, with studies showing benefits of early referral to palliative care services for patients with lung cancer [23], as well as psychological benefits for caregivers [24], and the high symptom burden in many patients with MPM [6], it is possible that more patients and caregivers would have benefited from earlier palliative care involvement. However, a randomised study reported no benefit in quality of life for MPM patients with early referral to a palliative care specialist compared to review once symptomatic [25]. Satisfaction with care may be enhanced by improving communication between health care professionals, as most patients had several health care professionals involved in their care and perceived a lack of communication between them.

The main sources of support were family/friends, GP, and medical specialists, with palliative care services valued more by caregivers. Caregivers highlighted additional support services they would have benefited from, particularly the opportunity to speak with other people (likely health professionals) without the patient present, psychological support for themselves, and respite care. After bereavement, caregivers would have appreciated grief counselling and a consultation with a member of the patient's medical or palliative care team.

The impact of caring for a loved one with advanced cancer cannot be overestimated. Studies have shown that psychosocial distress is often higher in caregivers than the person with cancer, and being a caregiver is a risk factor for high-symptom burden [26–28]. This is particularly challenging for families living outside major cities. One study suggested that a strong therapeutic alliance between the patient and oncologist not only improved patient outcomes but also benefited the caregiver, including possibly caregivers' adjustment to bereavement, with improved quality of life and distress 6 months after the death [29]. Bereavement support is generally organised by palliative care services, with complicated grief estimated to occur in 10–20% of caregivers [30]. Australian bereavement guidelines recommend contact be made with the family soon after the death and a preliminary bereavement plan developed based on caregiver needs, a pre-death risk assessment, and circumstances of the death. The caregiver should then be contacted 3–6 weeks and 6 months later [31]. There is little evidence available to guide these recommendations, and it is not clear how often they are implemented.

Our study has limitations. We were unable to determine the survey response rate as methods of recruitment included distribution of study flyers in two hospitals, advertisements in relevant MPM support organisation newsletters and websites, and a mail-out from icare. However, it is estimated that 70% of people in NSW with MPM are registered with icare and ~41% of patients and 45% of caregivers completed and returned the mailed survey. We acknowledge that this group may not be representative of the experience of all Australian MPM patients or caregivers, and there may be a self-selection bias in the study population.

The sample size is limited by MPM being a rare cancer with a short median survival. We chose to include bereaved caregivers as often only in retrospect are people able to reflect on their experience and articulate what may have been helpful. However, it is likely that the perception of the experience of caregivers earlier in the journey is different from those after bereavement, and this may particularly influence their decisional regret. Time from diagnosis of the person they cared for varied, so recall for those bereaved longer may be less accurate, and there may have been changes in treatment and supports in the interim. There is potential for a small overlap between MPM patients and the caregiver's person with MPM, but as 95% of caregivers were already bereaved, the overlap is very small. We have compared differences between patients' perceptions and caregivers but acknowledge some differences may result from being at different stages in the cancer journey. The bereaved caregivers are better able to reflect on the entire journey, but likely to be particularly influenced by how their loved one died, whereas the MPM patients were still well enough to participate in the study, and their perceptions are based on their experience to date. For future studies, more detailed insights into both patients and caregivers could be obtained using a mixed-method design combining qualitative and quantitative data, and by comparing findings to other tumour types.

Strengths of the study include the comprehensive nature of questions drawn from patient, caregiver, and health professional interviews. We endeavoured to involve participants from across Australia to ensure that the information was generalisable. The involvement of caregivers, particularly bereaved caregivers, is novel and highlighted a number of unidentified issues that can be addressed.

The study provides important information from people living with various stages of MPM, and from caregivers involved in the care of patients from diagnosis until after death. Although satisfaction with treatment received was generally high, we identified areas for improvement including greater public education about MPM; streamlining diagnostic processes; improved information resources about MPM, treatment options, and services available; improved communication between health professionals, patients and their families, and amongst health professionals, access to palliative care regardless of location, and improved bereavement services for families after the patient's death. There is a need to improve information and communication about MPM with patients and caregivers to improve patient and caregiver outcomes.

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Compliance with ethical standards

Competing interests Drs Vardy, Dhillon, and Kao report grants from icare Dust Diseases Care for the conduct of the study which is the basis of the submitted work. Dr. Kao reports personal fees to his institution from MSD, Roche, AstraZeneca, Pfizer, and BMS, outside the submitted work. Dr. Dhillon reports honoraria paid to her institution from MSD outside the submitted work.

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